SPINAL CORD

Vol. 8, No. 2

January 1997

Agent Orange Benefits Act of 1996 Becomes a Reality

On September 26, 1996, President Clinton signed the Agent Orange Benefits Act of 1996 into law. This is a landmark act that provides lifetime healthcare benefits, a monthly allowance and vocational training to the sons and daughters of Viet Nam veterans who were born with spina bifida.

For over 20 years, Viet Nam veterans have struggled to obtain recognition of the effects of the use of Agent Orange, a chemical herbicide used in Viet Nam from 1965-70. It is anticipated that this legislation will affect several thousand children and young adults with spina bifida in the United States, including a number in Arkansas. Actual numbers of those who will benefit are only estimates at this time.

Benefits will be administered by the Veterans Administration and will be based on the severity of disability of the qualified recipient. The regulations for this legislation are presently being developed and the legislation will go into effect on October 1, 1997.

In the meantime, families who believe that they may qualify for benefits under the Agent Orange Act may contact the VA Regional Office at 1-800-827-1000 with questions and to be added to a log of applicants. In addition, the Spina Bifida Association of America (SBAA) is also maintaining a log of applicants which will be forwarded to the VA when regulations are finalized. You may contact the SBAA at 1-800-621-3141.

ASCIA Scholarships Presented

Arkansas Spinal Cord Injury Association (ASCIA) presented their 1996 scholarships on September 3, 1996. ASCIA Scholarship Chairman Adrian Horton and his committee reviewed 16 applications to make the selections. "Application review was a very difficult process this year," said Horton. "We had many excellent applicants." Each of the four recipients received a \$500 scholarship to attend the college, university or training program of their choice.

ASCIA scholarship recipients for 1996 were: **Darrell Chalk** of Newport who will attend UCA, **Rozene Whitby** of Wynne who attends Eastern Arkansas Tech School, **Tim Carr** of Little Rock and **Cynthia Adams** of Judsonia.

Rollin' Razorbacks Go International

The National Champion Rollin' Razorbacks were one of four teams invited to compete in the first International Wheelchair Basketball Tournament in Madrid, Spain. In their first game, the Razorbacks fell to the European All Stars 47-29. The Razorbacks put forth a better team effort in the consolation game against the Australian team, but again had trouble adapting to the international rules, losing by three points.

On December 7 and 8, three days after returning from Spain, Arkansas opened their regular season at home with victories over the Wisconsin-Whitewater Warhawks and Denver Nuggets, before losing Sunday to the highly talented Dallas Mavericks. See page 8 for the remaining schedule.



SPINAL COURIER

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Co-Editors

The Arkansas Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

BUCKLE UP!

For Sale - Video

Attention: Hunters and Outdoorsmen

If your interests include deer hunting, four-wheeling, fishing, camping or boating and you use a wheelchair - we have the video for you!

Return to the Outdoors, produced by two ASCC Case Managers and featuring ASCC client Larry Wil-



son, is a 28 minute video full of exciting ideas to make the outdoors enjoyable and accessible. In this video you can see Mr. Wilson

demonstrating simple, inexpensive adaptions he has made to allow outdoor activities.

You can have your personal copy for \$25 by contacting the Arkansas Education and Resource Center on Spinal Cord Injury at (501) 296-1792 or (800) 459-1517.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Accessible and Adaptable Housing Available!

Dear Editor:

The Little Rock Housing Authority (LRHA) now has several fully accessible and adaptable units available. At the present time, efficiency, single and two bedroom units are ready for occupants, and LRHA is expecting to have more three and four bedroom units in the near future.

These housing units have attractive outdoor decks with ramps and accessible parking. Inside, these units feature five foot turning radius for both the kitchen and bathroom, lowered upper cabinets, three foot wide doors to all rooms, lowered light switches, food pan-

try and washer/dryer connections. All units have a refrigerator and cooking range (gas or electric) furnished.

LRHA is currently looking for individuals with disabilities who are interested in subsidized housing to occupy these new units. For more details about the other special features of these housing units, qualification requirements and applications, contact **Keith Guy** at **340-4703**.

Steve Eichorn Little Rock Housing Authority

Editor's Note: Per John Gould, ASCC Peer Support Coordinator, these apartments are nice! He heartily recommends that Spinal Courier readers go and check out these accessible units.

Evans Resigns

Grover Evans submitted his resignation as a member of the Arkansas Spinal Cord Commission in November. Mr. Evans recently assumed the position as the Director of the Arkansas Disability Determination Division for Social Security and cited his new responsibilities in that position as the reason for his resignation.

Serving the Commission since 1990, Grover served as Commission Chairperson from 1994 to 1996. The members and staff of the Commission extend their sincere appreciation for his service and commitment to providing services for people with spinal cord disabilities in the state and wish him the best of luck in his new position.

ConnectCare

(Continued from page 7)

ConnectCare has a statewide toll-free help-line (1-800-275-1131) and on-site outreach workers in Columbia, Jefferson and Pulaski counties. The outreach workers recruit physicians and educate Medicaid clients about the program. They also make presentations to community groups and help Medicaid recipients, local service providers and the community understand and work with the ConnectCare Program.

If you want to know more about ConnectCare, call the toll-free help-line at **1-800-275-1131** or Ron Stark, program manager, at the Arkansas Department of Health, (501) 661-2251.

HIGH PROFILE! Patti Rogers

This is the fourteenth in a series of articles profiling the ASCC Case Management program.

At the top of the ASCC case management program is Client Services Administrator, Patti Rogers. Patti came to the Commission in 1989 from the Department of Developmental Disabilities. In addition to her thirteen-and-a-half years working for the state, Patti has also worked in public schools as a guidance counselor and a physical education instructor.

Patti received her B.S. degree in education from Harding University and her M.S. degree in counseling from Arkansas State University. Her responsibilities at the Commission include: training new Case Managers, supervising, coordinating and monitoring the thirteen Case Managers throughout the state, as well as case management secretaries. Patti is also responsible for reviewing referrals and authorizations for services and monitoring case service expenditures.

Training conferences are scheduled for the case management staff two times each year. Patti is responsible for arranging speakers for these sessions, as well as making sure the program will prove informative and useful to the Case Managers in providing effective services to clients.

In the course of a month, Patti may be in several different parts of the state visiting with Case Managers. She is always available wherever she is in the state to respond when Case Managers have problems. As one Case Manager said, "I can always count on Patti to help find a creative solution to any problem I might have. Her door is always open."



FAMILY MEMBERS: Me, eight cats and two dogs.

PHRASE THAT BEST DESCRIBES ME: Very committed, fair-minded and listens well.

FAVORITE WAY(S) TO UNWIND: When I have a lot of time, it's spending the day on the lake in my boat. Otherwise, I'm listening to music and reading a good book.

HIDDEN TALENTS/HOBBIES: Writing poetry - something I've been doing since about age 15. I have had several poems published. Also, refinishing furniture, cooking and apparently raising animals.

ACCOMPLISHMENT I'M MOST PROUD OF: The most recent is that I've been able to purchase five acres of land and will be building a new house in the immediate future.

SOMETHING I'D CHANGE ABOUT MYSELF IF I COULD: My tendency to start numerous projects simultaneously.

LAST GOOD BOOK I'VE READ: *The Runaway Jury* by John Grisham.

MY DREAM VACATION WOULD BE: Trip to Switzerland and train ride through the Alps.

MOST IMPORTANT THING I'VE LEARNED AS A SUPERVISOR: Listen, be open, be flexible and remember you were not always a supervisor. If you always remember where you came from, it's easier to understand those you supervise.

BEST ADVICE TO SOMEONE WITH A DISABILITY: Be involved, stay focused and be in charge of your own life.

SPINAL COURIER -----

From the Director

Happy New Year!

I hope 1997 brings each of you many opportunities and challenges. It seems to me that most opportunities bring with them a challenge, and vice versa. Each time we get an opportunity or a chance to do something new or progress, it comes with a set of obstacles, or at least bumps, to overcome to achieve it. By the same token, those experiences that seem to challenge us and summon us to thought or action often seem to bring "a silver lining" or an opportunity with them. We all are faced with opportunities and challenges everyday in our lives. Some are small, so routine, we hardly notice them while others shake us to the bones (with a combination of fear and excitement).

1997 will bring lots of opportunities and challenges to each of us. Here at the Commission, we are facing the challenge of lots of new clients with few additional resources to provide needed services to them. We're taking this opportunity to reevaluate how and to whom we provide services. We think there are ways we can better utilize our resources, staff, funds and equipment to do a better job and provide services to those who need them. We're excited about the chance to make changes. You will be hearing more about them as we progress in our plans.

I hope you seek out opportunities and challenges that keep you interested, excited, involved as we meet the new year.

Cheryl L. Vines

With Thanks

The Arkansas Spinal Cord Commission accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / (800) 459-1517 / tdd (501) 296-1794, or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

Donations This Quarter From:

Shirley McCluer, M.D.

The Family of John Rose

In Memory of Dr. Allen Hill:
Dr. Ronald Williams
Mr. and Mrs. Vic Mandeville
TCS Orthopaedic Clinic
Luna Craver
Hope Keiser
Dr. and Mrs. Bruce Brown

Wheelchair Maintenance Training

The Arkansas Spinal Cord Commission (ASCC) will be having a free wheelchair maintenance training session Saturday, February 1. The training, for ASCC clients and their family members, will begin at 10:00 a.m. in the

front Conference Room at Health-South Rehabilitation Hospital of Fort Smith, located at 1401 South J Street.

Preventive maintenance, basic repairs and making adjustments

will be some of the topics addressed during the training. This session will cover **manual** wheelchairs only.

If you would like to attend or need more information, please call John Gould at (501) 296-1784 or (800) 459-1517.



Participants at a recent training session included (left to right): Joshua DePriest, Donna DePriest, Brandy Romandia and David Romandia.



Karen Schmidt is being taught by John Gould how to use the Wheelchair Maintenance Manual to repair an armrest.

Urinary Management and Complications

By Shirley McCluer, M.D., ASCC Medical Director

Many Spinal Courier readers probably remember the many pages of questions that you answered for your Case Manager in 1995 when the Spinal Cord Commission did a survey of complications following spinal cord injury. This is a report of the results of that survey regarding urinary management and urinary complications. It should be noted

that this summary is based on the response that was given on the survey with no attempt to correct possible errors or misinformation Some of the answers suggest that the person giving the answer did not understand the question.

Participants: 577 surveys were analyzed, with the results as shown in Tables 1-5.

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Discussion: The reason such studies are done is to better understand what might happen to people with new injuries and to hopefully learn how to prevent future complications. You should be able to compare your experience with individuals who have similar injuries and see if you are typical or different. It is easy to see that some complications are more likely to occur with some methods

of bladder management than with

others.

Because some of the groups are small, one should be cautious about drawing conclusions. However, it is obvious that far more females use an indwelling catheter than males. No one has been able to devise a satisfactory external urine collector for women, so this is not an option for them. It is more difficult for women and for quadriplegics to do self-catheterization, especially when sitting in their wheelchair. This probably explains the difference in the use of indwelling catheters. Although not shown in the tables, 33.9% of male paraplegics do intermittent catheterization, compared to 11.4% of the quadriplegics. In females the difference is even greater, 39.2% of the paraplegics and only 5.3% of the quadriplegics do intermittent catheterization.

Infection: With ideal urinary management, it is hoped that no urinary infections will occur, because each episode of acute infection probably causes a little more permanent damage to the kidneys. The number of episodes in persons who do intermittent Continued on Page 7 - See" Urinary Mgmt."

Table 1 Level of Injury:

	Number	Para	Quad
Male	465	54.6%	46.4%
Female	112	66.1%	33.9%

Table 2 Method of Bladder Management:

	Male		Female	
Intermittent Catheterization	110	(23.7%)	31	(27.7%)
Indwelling Catheter (Foley)**	126	(27.1%)	44	(39.3%)
External Collector (condom)	117	(25.2%)	1	(0.9%)*
Ostomy	28	(6.0%)	16	(14.3%)
Other	84	(18.0%)	20	(17.9%)

Table 3 Number of Urinary Infections in the Past Year in Males

	None	1-3	More than 3
Intermittent Catheterization	32.7%	50.5%	17.4%
Indwelling Catheter (Foley)**	31.0%	37.3%	31.7%
External Collector (condom)	47.0%	41.0%	12.0%
Ostomy	60.7%	25.0%	14.3%
Other	77.4%	17.9%	4.8%

Table 4 Number of Urinary Infections in the Past Year in Females

	None	1-3	More than 3
Intermittent Catheterization	41.9%	19.4%	38.7%
Indwelling Catheter (Foley)**	34.1%	34.1%	31.8%
External Collector (condom)	0.0%	0.0%	100.0%
Ostomy	37.5%	43.8%	18.8%
Other	50.0%	30.0%	20.0%

Table 5 Number Experiencing:	Bladder Stones		Kidney Stones	
	Male	Female	Male	Female
Intermittent Catheterizatrion	18.2%	12.9%	10.9%	16.1%
Indwelling Catheter (Foley)**	47.6%	20.5%	31.7%	13.6%
External Collector (condom)	17.9%	100.0%*	25.2%	0.0%
Ostomy	46.4%	18.8%	46.4%	18.8%
Other	15.5%	15.0%	10.7%	15.0%

^{**}Includes both suprapubic and urethral (Foley) catheters.

^{*}This response is probably an error.

Americans with Disabilities Act Now on the Internet

The United States Department of Justice (DOJ) has established a home page on the internet for the Americans with Disabilities Act (ADA). Now you can learn about the ADA while sitting in front of your home or office computer. The Department of Justice created the home page to better inform Americans about the law's requirements and the technical assistance materials available for its compliance.

Features available on the ADA home page are:

- The complete text of the law and associated materials.
- A technical assistance program available from the DOJ.
- Technical assistance materials and regulations.
- A guide to disability rights laws.
- An ADA guide for small businesses.

- Commonly asked questions about service animals.
- New or proposed regulations related to ADA.

The internet address of the ADA home page is:

http://www.usdoj.gov/crt/ada/ad ahom1.htm

However, we could not access the home page directly. Instead we had to first go to the DOJ home page and then link from there. So, you may need to start with: http://www.usdoj.gov/

The ADA, which was signed into law on July 26, 1990, prohibits discrimination on the basis of disability in employment, programs and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities.



MS Patient Education Network

Now you can have 24 hour free access to "The MS Patient Education Network" from the privacy of your own home simply by using your phone. This automated service gives Multiple Sclerosis patients, their families and support groups a convenient way to get the latest information on MS. You can:

- Listen to a replay of "New Perspectives on Living with MS."
- Hear "Best of Health Talk" featuring highlights from several programs.
- Hear the most commonly asked questions and answers on MS issues.
- Listen to information on specific topics.
- Register for one of the upcoming semi-monthly live programs.
- Participate in a national MS patient survey.

Just call **1-800-335-2500** to listen, participate or register.

Web Brings the Wide World Home

If you have a computer and you're not on the internet, you may want to consider it. The internet, or the World-Wide-Web, allows you access to thousands of individuals and sources of information around the world, and all of it can be accessed from the computer in your home. The cost of acquiring this access is modest. Depending on where you live, you can usually get online for about \$20 per month with unlimited access.

So, exactly what can you do online? Well, you can send e-mail messages to friends, who are also online, across the street or across

the ocean without incurring long distance fees. You can communicate with people from around the world who have the same interests as yourself. You can visit the White House and sign their guest book or you can visit NASA and view the latest photos of Europa, one of the moons of Jupiter.

This may sound pretty exotic and even scary, but it's really quite interesting, fun and educational, and computers are cheaper and easier to use than ever. One word of caution, though, being a web surfer can be addicting. There is always one more site to visit and

another link not yet taken. Here are just a few of the Web sites relating to individuals with disabilities:

- Cure Paralysis Home Page: http://www.cureparalysis.org
- New Mobility: http://www.newmobility.com
- University of Alabama SCI Page: http://www.sci.rehabm.uab.edu
- Wheelchair Access Inc.: http://www.inet-usa.com/wca/

ConnectCare - A Bridge to Better Medical Service

By Dr. Sandra B. Nichols, Director, Arkansas Department of Health

Between July 1995 and June 1996, almost 100,000 Medicaid clients were treated in emergency rooms in Arkansas, at a cost of more than \$4.5 million. While many of these patients needed emergency care, others had problems that could have been treated in a doctor's office. Taking care of minor injuries and illnesses in the emergency room diverts ER staff from more serious cases and, ultimately, raises health care costs for all of us.

To help with these concerns, Medicaid is introducing Connect-Care, a new way of linking Medicaid recipients with Primary Care Physicians. The Primary Care Physician (PCP), or "family doctor," is the main source of health care for Medicaid patients. The PCP acts as a "gatekeeper" for most Medicaid services. This means that clients have to get approval from their PCP before they can get services from other health care providers. This way, the PCP can refer them to the services they need. The PCP makes sure that their patients can get care 24 hours a day, seven days a week, when they need it. Primary Care Physicians monitor their patients' health and educate them on staying well.

Since 1994, when Medicaid began signing up clients with Primary Care Physicians, more that 1,500 doctors in Arkansas and border areas have become Medicaid PCP's. Several different kinds of doctors can be PCP's, including general and family practitioners, internists, pediatricians and obstetrician-gynecologists. Even certain kinds of clinics can qualify. Clients can choose the doctor who is right for them. Doctors are paid a small monthly fee for managing each patient's

care, in addition to fees for office visits and other services.

Some Medicaid clients do not have to have a PCP. For example, clients with **Medicare** as primary insurance, Children's Medical Services clients and residents of nursing homes do not have to have a PCP.



More than 150,000 Medicaid recipients in Arkansas now have a PCP, almost 80 percent of

all who are eligible to sign up. Patients who have a Primary Care Physician have been shown to have an easier time getting medical care than patients who are not in the program. Also, the care they receive is better managed and less expensive than patients who do not have a PCP. In the first 17 months of operation, the program saved an estimated \$30 million by shifting more care to PCP's. Studies have shown it can save even more tax dollars if the last 40,000 Medicaid clients sign up with a PCP and if more Medicaid recipients learn to go to their Primary Care Physician instead of the emergency room for minor problems.

ConnectCare is a new education effort that builds on these successes. It has three main goals:

- to encourage the last 40,000 eligible clients to select a Primary Care Physician, or "Family Doctor";
- to teach clients how to use services wisely, using preventive services instead

- of high-cost emergency room services; and
- to influence clients toward a health lifestyle.

(Continued on page 2 - see ConnectCare)

Urinary Mgmt.

Continued from page 5

catheterization is of special concern because this is generally considered to be the safest method of management. The persons in this group who are having repeated infections should reevaluate their catheterization routine and procedures. When an infection occurs in anyone, it is not enough to treat it with antibiotics to get rid of the symptoms. A careful review of possible causes should be done in order to try to prevent future episodes!

Stone Formation: Bladder stones occurred in 147 individuals, 27.3% of the males, but only 17.9% of the females. As seen in Table 5, even the females who use indwelling catheters had significantly fewer bladder stones than males (20.5% compared to 47.6%). The high percentage of stones in persons who have a urinary ostomy may refect what occurred prior to the ostomy. This needs further study.

Kidney stones are more serious than bladder stones, but they occur somewhat less frequently. One hundred thirteen persons out of the total group reported kidney stones, 20.6% of the males and 15.2% of the females. Table 5 again shows that fewer women with catheters have kidney stones than men.

Anyone who is interested in more detail about these results may contact Dr. McCluer at 296-1788.

SPINAL COURIER —

New Items in the AR Education & Resource Ctr.

No Pity (narrated by Christopher Reeve), this documentary is an hour long video which features several people with disabilities who discuss how they deal with their disabilities and life in general. (This program was originally broadcast on HBO and a copy was donated to the Resource Center by an ASCC client.)

Take Control, Volume 1 (the PC Version of the CD-ROM), a multimedia guide to spinal cord injury, is now available for purchase at a cost of \$55, which includes shipping and handling. Take Control can be used as a tutor, a learning game and an encyclopedia on SCI. This full color, one hour and 50 minute, entertaining and educational CD features peer guides and resource lists, and contains 26 interactive video segments, 35 printable documents and a multimedia glossary.

Please contact the Arkansas Education and Resource Center on Spinal Cord Injury (call **501-296-1792** or **800-459-1517**) for details and to obtain your order form.

> BULK RATE US POSTAGE Little Rock, AR Permit # 3168

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1997 Basketball Schedule

Rollin' Razorbacks

January 24-25-26 AWAY Nashville

February 22-23 HOME* U.S. PIZZA CO. • COORS LIGHT •

UNITED MEDICAL CO.

INVITATIONAL

Austin, Dallas (Mavericks), University

of Texas Arlington

March 1-2 AWAY Dallas, Austin, Houston, Arkansas

March 21-22-23 HOME* REGIONALS DIVISION I

April 3-4-5-6 AWAY FINAL FOUR

Birmingham, Alabama

Fort Smith Shootin' Stars

March 8 AWAY SECTIONALS

March 22-23 AWAY REGIONALS DIVISION II

Sherwood, Arkansas

Junior Rollin' Razorbacks

Feb. 8-9 HOME Hot Springs

Garland County Community College

March 22-23-24-25 AWAY JUNIOR NATIONALS

Charlotte, North Carolina

*Home games will be played at Sylvan Hills High School (Hwy. 107, North of Sherwood, AR)

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Commission Members: Sheila Galbraith Bronfman - Little Rock (Chair) Grover Evans - Little Rock Sloan Lessley - Calico Rock Russell Patton - Jonesboro Sandra Turner - Little Rock

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